DOCUMENT RESUME

ED 289 289 EC 201 250

TITLE	Transition Summary, 1986.
INSTITUTION	National Information Center for Handicapped Children and Youth, Washington, DC.
SPONS AGENCY	Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE	Mar 86
CONTRACT	G0084C3500
NOTE	8p.
PUB TYPE	Collected Works - Serials (022)
JOURNAL CIT	Transition Summary; Mar 1986
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Community Programs; *Deinstitutionalization (of Disabled); *Group Homes; *Mental Retardation; Parent Materials; *Parent Role; *Program Evaluation; Residential Programs; State Programs

ABSTRACT

Two articles examine issues of transition for people with mental retardation. The first article describes how the Ohio Association for Retarded Citizens (ARC) developed a parent-based project to monitor the quality of residential placements. The project was intended to assess both the strengths and weaknesses of community residential programs, to provide statewide feedback on service delivery, to develop a method by which citizens and service providers can work together to improve services, and to ensure individuals with retardation the opportunity to live in community settings which accommodate their individual needs with a minimum of restriction. The second article reviews one parent's experiences with her retarded daughter's struggles for independence. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED289289

TRANSITION SUMMARY

Information from the
National Information Center for
Handicapped Children and Youth

1986

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

✓ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

EC 201250

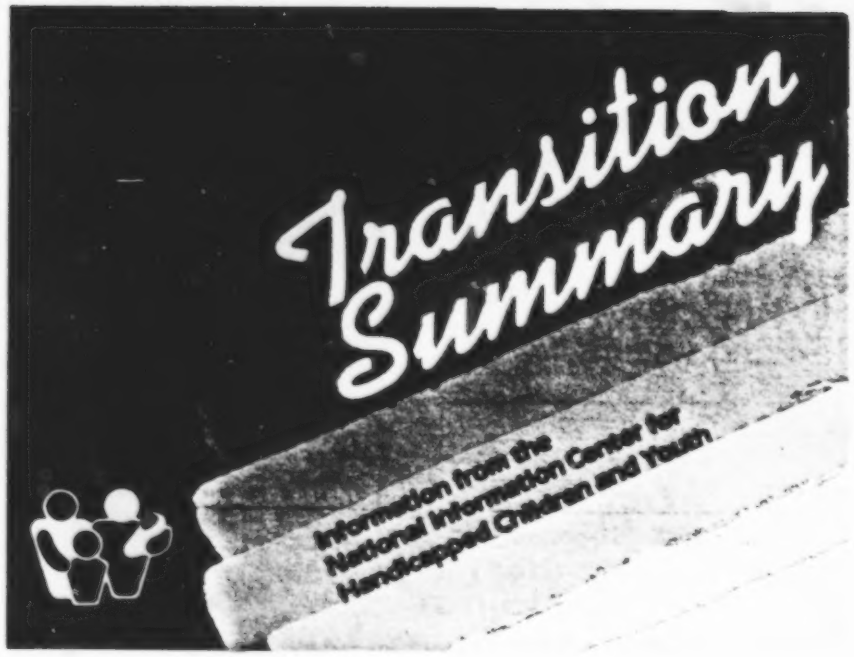
BEST COPY AVAILABLE

3376

Making Sure a House Is Still a Home

By Hank Bersani, Jr.

In the State of Ohio, as in virtually every state in the country, there is a growing trend to move people with mental retardation from state institutions into less restrictive residential settings. The Ohio Association for Retarded Citizens (ARC-Ohio), like many other parent organizations, has been supportive of this trend. However, at the same time, as an advocacy organization, there was concern that the community placements which people were moving into were of mixed quality. The concerns led the organization to develop a parent-based project to monitor the quality of residential placements.



MARCH 1986

Who Currently Monitors Residential Services?

As it turns out, there are many answers depending on where one lives. Homes that are funded by Medicaid, such as Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), are administratively approved and reviewed by the Health Care Financing Administration (HCFA). Other programs that are fully or partially funded by state offices of Mental Retardation and Developmental Disabilities are usually reviewed by them. Residences are "checked on" for fire safety by local fire authorities. Most programs have staff who are charged with some responsibility to safeguard quality: case managers, program coordinators, house managers, and so on. Many residences are also certified by such bodies as The Commission on Accreditation of Rehabilitation Facilities, Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons, and The Joint Commission on Accreditation of Hospitals. Family members and neighbors who visit on a regular basis can be said to be monitoring the quality of care in the program.

As in other states, residences in Ohio are already monitored by several agencies. Some of the programs experienced additional program reviews as a part of a consent agreement from a class action lawsuit over conditions in state institutions.

Why Is There a Need for Additional Monitoring?

At first glance, one might assume that there was more than enough monitoring in place already. However, ARC-Ohio determined that this was not the case. We felt there was a great need for an additional type of monitoring for two reasons. First, existing safeguards were clearly insufficient because poor conditions existed in several residences across the state. ARC-Ohio is dedicated to the position that deinstitutionalization can succeed, and that problems in existing homes should be seen as failures in *implementation*, rather than failures of the *concept*. Second, existing monitoring efforts were of a limited scope. Most forms of monitoring are formal, and reflect the concerns, assumptions and points of view of professionals. While these approaches have their value, ARC-Ohio, as a parent/advocacy organization, has an equal concern for the perspective of family members, and the point of view that develops from a non-professional involvement. ARC-Ohio determined the need for a parent/advocate oriented monitoring approach that could augment (*not* supplant) existing monitoring efforts. The need was for a method that was formalized enough to be useful, but not so routinized that it amounted to a checklist of only the most mechanical concerns (number of toilets, temperature of water at the tap, etc.). These matters can be quite important, but should be adequately handled by formal, professional review.

EC 801250

"Concerned parents, family members, and friends already have the two major qualifications to be monitors: they are well aware of what it means to live successfully in a home in the community and they have the unique perspective that is lacking in existing systems."

Why Are Parents/ Advocates an Important Resource for Monitoring Residences?

Concerned parents, family members, and friends already have the two major qualifications to be monitors: they are well aware of what it means to live successfully in a home in the community and they have the unique perspective that is lacking in existing systems. If necessary, a group of parents/advocates could set out to monitor community residences with little or no support, and make a significant impact on the quality of the service system. However, with the support of a small grant from Miami University in Oxford, Ohio, ARC-Ohio developed a schema for a statewide, parent-based, residential monitoring project. It is a model that we feel can be easily replicated in other states across the country.

What Were The Basic Goals of The Project?

We began by identifying the following four goals:

1) To assess both the strengths and weaknesses of community residential programs;

2) To provide statewide feedback on how services are delivered by providers, and received by individuals who live in the residences;

3) To develop a constructive method by which citizens and service providers can work together to improve the services to persons with mental retardation; and

4) To ensure that persons who experience mental retardation have the opportunity to live in community settings which accommodate their individual needs with a minimum of restriction.

In line with our goals, we decided there were two tools that needed to be developed to help the monitors do their jobs:

1) A uniform monitoring instrument composed of open-ended questions based on a set of philosophical statements.

2) Additional written support materials, compatible with the evaluation instrument, which contain basic information about residential services.

ARC-Ohio has published an evaluation instrument, *Monitoring Residential Services: Guidelines*, and a companion volume of support information, *Monitoring Residential Services Handbook*. The *Guidelines* addresses major areas of residential quality, followed by several dozen open-ended questions which address each of these areas.

Rights. Human, civil and legal rights are held by all persons. These rights are not forfeited merely by living in a community residence. Service providers are obligated to respect and protect all aspects of the rights of the people who live there. Residential services have added obligations to *teach* people about their rights and to *assist* them in the daily exercise of their full range of rights.

Environment. First and foremost, a community residence is a home. Its function as a "program," "service" or "agency" is clearly secondary. Efforts must be made to create a physical and social environment which is "homelike," comfortable, and which asserts the humanity of the people who live there. The residence should not draw any undue attention to the location or the people who live there.

Staff. Direct care staff are the individuals who actually provide the service received by the people who live in the residence. Because staff may care for people whose needs are quite challenging, they must be well trained, well supported, and well supervised.

Commitment to Personal Growth. A community residence must provide needed supervision and support in an environment which also allows opportunities for growth and development through a variety of experiences. By assuming the responsibility to provide a residential service, an agency and its staff also accept the obligation to provide a diverse range of living and learning experiences. These experiences must include a *normative* amount of exposure to *reasonable* levels of risk. Learning occurs in an environment with manageable failure and meaningful successes.

Use of Community Resources. Although living near resources is desirable, it is even more important that those resources be *used*. The people living in a community residence must have systematic opportunities to use community resources on a regular basis. Resource use should be in small groups (1 or 2) whenever possible. Each individual should experience a *variety* of community experiences appropriate to his/her age and interests. The residential provider is required to demonstrate a commitment to the normalizing use of community resources and community participation for all people who live in the home.

The instrument focuses on the fact that community residences are first

and foremost *homes*. The job of the parent monitor is to assess the quality of a home, rather than a "facility" or a "program." The monitoring visit is focused on identifying indications that the house may not be a home. We offer our monitors the following guidelines:

First, tour with empathy. Think of the residence, not as a "place for them," but as a home for someone like you. Ask yourself "If I lived here what would I want?"

Second, focus on the conditions you see rather than the excuses for those conditions. If you see something wrong, an invasion of privacy for example, focus on that fact from the point of view of a person living that experience. Then, the "reason" that there is not sufficient staff to offer privacy is not an acceptable "excuse." It may be a practical reality, but if parent monitors do not speak up, do not expect anyone else to.

Third, use your own living arrangements as a standard. This does not mean that we all have to live in the same kinds of houses, or put up with each other's taste. It does mean, however, that a residence that is "better than where they lived before," or one that is "good . . . for a group home," is not good enough.

What Is the Ultimate Role of a Monitor?

Many of us have been brought up with the old cliché that you should not criticize something unless you have a solution. I no longer believe that, and I feel that it represents an attitude that is detrimental to the exercise of parent-based monitoring. We need to think of a monitor as a smoke detector. Its job is to keep watch, and sound an alarm if there is a *possibility* of a problem. Smoke detectors occasionally sound false alarms. Burned popcorn or dust may set them off by accident. But we do not expect them to put out the fire they warn us about, and we tolerate false alarms, because they are far better than not being alerted to a dangerous situation. Monitors may have concrete solutions to problems they identify. If they do, so much the better. But this is *not* a prerequisite to criticism.

"We need to think of a monitor as a smoke detector. Its job is to keep watch, and sound an alarm if there is a *possibility* of a problem."

It is important for everyone involved in the monitoring process to understand what it can and can not do. Such monitoring is not intended to take the place of administrative supervision licensure or certification. The presence of a volunteer-based monitoring project does not relieve officials from their statutory responsibilities to supervise care and ensure quality. Our monitoring project is designed specifically to support and enhance existing residential safeguards. It is not intended to supplant governmental supervision. It is our belief that all of the existing safeguards and monitoring approaches are needed in addition to private, voluntary, parent and citizen-based efforts.

Hank Bersani was the 1985 Fellow in Public Policy in Mental Retardation at The Joseph P. Kennedy, Jr. Foundation. As of January, 1986, he is the project director of a Research and Training Center for the Study of Community Integration. Additional information about the ARC-Ohio Residential Monitoring Project is available from ARC-Ohio, 751 Northwest Boulevard, Columbus, Ohio 43212.

Coming of Age

By Lotte E. Moise

Coming of age, when you have a disability, is tough. Unfortunately, parents sometimes make it tougher.

Parenting is never easy, nor is it a task with an endpoint for anyone. Being the parent of a son or daughter with a disability automatically adds another dimension. It puts one on the alert against the rest of the world. There are voters, professionals, legislators, bureaucrats and policymakers out there who will ultimately affect the quality of their lives, and whom we constantly have to convince, persuade and educate.

We parents tend to be of divided heart as we prepare our offspring for a future, and for a future without us. As group advocates we fight like tigers for our cubs' right to education, treatment and habilitation. As individual mamas and papas we often act more like kangaroos who keep their young ones in a protective body pouch. Not that we are all alike. It is sometimes difficult to let our children take risky steps towards independence. We fear for their safety and want to hold them close. But let us be honest. Nobody can guarantee a secure future to their children, be they brilliant or handicapped. The future holds no promises for anyone.

I once heard a young woman with a severe physical disability speak at a conference. "Of all the oppressed minorities," she said, "we are the only one where the parents tend to be on the side of the oppressors." I fervently hope that our family has not put too many roadblocks in our daughter Barbara's passage to adulthood.

If we have helped rather than hindered, it is because she taught us to listen. Now I know and believe with all my head and heart and soul that she and "allbody" (a word coined by Barbara) have the same inalienable right to full citizenship, to mainstream living—to neighborhood and hometown participation. How we learned was a family process that began when she was very small.

Barbara, who is now 31, was a normal looking baby, much welcomed by a four-year-old sister and a two-year-old brother. She developed

"What I did not realize at that point, nor did I think of it until later, was that I was robbing our daughter of one of her fundamental rights—the opportunity to learn an essential skill, namely to make appropriate choices."

painfully slowly, but we did not begin the rounds of experts until she was over a year old. The words "mental retardation" were not spoken until she was a year and a half. Like most mothers of a child with a developmental problem I wondered and worried a lot, and automatically this worry translated into decision making for our child. I remember that I feared for her future as a woman. Secretly I made my mind up right then that our girl child would not be able or allowed to have relations with the opposite sex—that alcohol would be a No-No and that she would always live with us. What I did not realize at that point, nor did I think of it until later, was that I was robbing our daughter of one of her fundamental rights—the opportunity to learn an essential skill, namely to make appropriate choices. For to be able to choose is to take a step towards decision making—which is how we develop judgement—and judgement leads to becoming a responsible, respected adult.

When I finally did think of it again it translated into an important learning experience for our entire family. If "choosing" was indeed a learned skill, then it was important that Barbara be given that opportunity like the rest of us, and so our family group of five reinforced each other as we strove for the true meaning of "choice."

The dictionary defines choice as the "voluntary act of selecting or separating from two or more things that which is preferred." I can think of several ways in which we let Barbara "select." Even when she was little she came to restaurants with us (yes, we stared down the starers) and we encouraged her to order from a menu, though we had to (and still do) read to her from it. That is probably why she loves that gourmet establishment with the golden arches where you don't need to read a menu! She would also come to the library with us and check out picture books and records to play on her phonograph.

Unfortunately, there were occasions which I remember with a red face, when I was the one who put obstacles in the way of her "voluntary act of selecting that which is preferred." She announced one day that she wanted to grow her hair long "like my sister." "No!" I said firmly. "You look very nice with short hair, and it's a lot of work to take care of it when it's long. You have to rinse it more when you wash it, and then you'd have a hard time putting it up in curlers. So wait until you are bigger!" As far as I was concerned the subject was closed. When sister Karen heard of the fuss, she went to bat for Barbara. "Why not, mother? Why shouldn't she? Everybody is wearing their hair long these days." Reluctantly I gave in, and for years Barbara wore her hair long, and managed to take care of it nicely. Significantly, it was I, her mother, who had interfered with her decision making. I was the slow learner!

Years have passed, and it is clear to me now that parents need sensitive feelers and listening ears in order to tune in to our sons' and daughters' wishes and needs and fears—in order to observe even those of our people who have severely impaired hearing and speech. These skills are an essential prerequisite to the newly available electronic communication devices. I have always had to watch for question marks in Barbara's eyes, and even now—at 31—when she comes home for weekends and bubbles with news and information in her somewhat fractured English, I have to stand still, come closer, and feel for the essence of her messages.

These messages, now that I look back on them—have flagged the major milestones in her life. The Barbaras of this world have shown us the way and we have learned to follow.

I don't think we would have had the courage to let our young adult daughter move away from home at age 18 if she had not clearly and frequently asked us to let her go. It began with small things. Like the time when she was 16, and my husband and I assumed that she would go to a concert with us. "I'm not going!" she declared firmly. "Oh yes you are!" we told her. "You always go." I was afraid to leave her home alone, although we lived on a quiet country road and had a dog. So I cajoled and pressured her a little longer. Finally she burst out in exasperation: "I hate that kind of music (classical) and I want my peace!" With this outburst she accomplished a small bid for independence. She had asked for a quiet evening at home alone and for a change we listened.

There were many more scary and risky steps which at first gave us heart failure, like teaching her to strike a match and light a fire in the stove, crossing a street, a first solo bus ride and unchaperoned outings with her brother or sister, and boys! The alcohol No-No took care of itself also. She prefers cokes.

Barbara's bid for independence became stronger as she grew older. One time she was very upset because a neighbor had died. We tried to answer her questions about death as best we could and hoped she felt better. A few weeks later she and I were having an argument. I nagged. She was angry, and suddenly she looked at me and asked: "When are you going to die, Mummy?" I was

shocked. Death is the one condition that we cannot change for our children. So I put my arm around her shoulder. I assured her that I was feeling fine and should be good for a long, long time. "But why do you ask, Barbara?" Her answer was: "'Cause then I will be free."

From then on it was only a matter of time until she was eager to move away from home like her brother and sister. She had experienced small adventures away from us since she was a little girl. At first it had been an overnight with friends "just for fun," then summer camp, later an exciting week staying with Karen and David in their university dormitories. The final impetus came when she stayed in a Copehagen group home for a month while I studied Danish residential programs. When we returned home from there she declared: "I wanna go someplace like Karen and David." And we let her go. We decided that we could not let our fears and apprehensions be her straightjacket.

For 12 years she has lived away from home now and has been in six placements which have ranged from poor to mediocre to excellent. Life has tested and strengthened her through sadness and joy. She misses her father, since his death four years ago, with constancy and loyal love. She loves her boyfriend of many years and wishes that they could live together as a couple. She is more assertive towards me and knows when to speak up firmly.

With all her warmth, perceptiveness and social skills, Barbara has not yet become a highly motivated or ambitious worker. Without her disability she might have been a great social director! She understood the word and the concept of money at an early age. Our society had already left its imprint on her. If she understood money then she would eventually connect money with work. I wish that it were so. She is a great consumer and knows how to spend and stuff, but it does not seem to motivate her to be a good worker.

Fortunately, we are now beginning to understand the importance of vocational testing and workplace experiences for even our most disabled people. Marc Gold sparked the movement. The Danes and Swedes were already providing sophisticated vocational training to junior high school aged "special" students back in 1971. In 1972 when I visited the ENCOR program in Nebraska they had begun work stations in industry: in a furniture factory, a Holiday Inn and a hospital. I am encouraged and echo the urgency with which Jean Elder, Madeleine Will and many young parents of children in public schools are clamoring for early transitional work training, so that our young adults will be ready to take their place in the mainstream work force.

Unfortunately, this may come too late for some of our older sons and daughters for whom vocational testing was unavailable, and whose work experience is limited to repetitive uninspiring tasks. I hope not. I hope that the future will hold meaningful work activities for all our adult sons and daughters. Work activities that will strengthen their self-esteem and sense of worth.

And remember the principle of "the developmental model"? "One success leads to another?" Our students, trainees and residents continue to prove that there is no cutoff point to growth in any human being, be they slow or fast—young or old. Our entire family has grown with Barbara. I have certainly grown in advocacy skills as a parent, and expect to continue to hone these skills as long as there are goals to reach and obstacles to remove.

The theory of the developmental model has culminated in the self-advocacy movement. A generation of persons with disabilities for whom we thought we would have to speak forever, are now speaking for themselves. Twenty-five years ago we told the legislators and policymakers that "our children are more like others than they are different." It seems that they believed us and now *know* that they are "People First." PEOPLE FIRST chapters (by this and other names) are making their voices heard in Canada, many states of our country, in Europe and Australia. They are learning to run their own meetings complete with agendas and election of officers. They plan social events, support and oppose legislation, and strive for full partnership and participation in organizations that affect their lives. I believe that we the parents and professionals can make no better contribution to the future of our sons and daughters than to give our wholehearted support to their young movement, which is the ultimate proof of their coming of age.

"The theory of the developmental model has culminated in the self-advocacy movement. A generation of persons with disabilities for whom we thought we would have to speak forever, are now speaking for themselves."

Lotte Moise has written As Up We Grew With Barbara, *an account of her family's experience in raising Barbara. For information about the availability of her book, write Ms. Moise at 30401 Sherwood Road, Fort Bragg, CA 95437.*

This newsletter was developed by Interstate Research Associates, Inc. pursuant to Cooperative Agreement G0084C3500 with Special Education Programs of the U.S. Department of Education. The contents of this publication do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products or organizations imply endorsement by the U.S. Government.

This information is in the public domain unless otherwise indicated. Readers are encouraged to copy and share it, but please credit the National Information Center for Handicapped Children and Youth.

Transition Summary is a product of the National Information Center for Handicapped Children and Youth under Cooperative Agreement G0084C3500 between the U.S. Department of Education and Interstate Research Associates, Rosslyn, VA. The contents of this publication do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products or organizations imply endorsement by the U.S. Government.

For a free subscription to future issues, write NICHCY, Box 1492, Washington, DC 20013.

Project Director . . . . . Toni Haas
Editor . . . . . James Murphy

National Information Center for Handicapped Children and Youth
Box 1492
Washington, D.C. 20013

MOVING?
Please send your new address along with your old mailing label to NICHCY, P.O. Box 1492, Washington, D.C. 20013.

BULK RATE
U.S. Postage
Arlington, VA
Permit No. 586

Address Correction Requested

Become Part of The National Exchange Network

With this newsletter, The National Information Center for Handicapped Children and Youth continues a two-way flow of information with you, the concerned people in communities across America. Let us know about the projects you are developing, the progress you are making, and the good things that are happening in services for the handicapped where you live. If we can hear from you, we can share your information with many others who will find it useful, and, of course, we will give full credit to the originators. Address your responses to: Toni Haas, Director, The National Information Center for Handicapped Children and Youth, 1555 North Wilson Boulevard, Suite 308, Rosslyn, Virginia 22209.